

Connecting the Dots for Caregivers

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CONNECTING THE DOTS FOR CAREGIVERS



Inspired by a Community of Caregivers

While every situation is unique, one thing is clear, family caregivers do whatever they need to do to make sure their loved one has the support they need. For many, this means providing care 24 hours a day, seven days a week.

This past August, the *Connecting the Dots for Caregivers* project team had the privilege of meeting with 251 family caregivers and healthcare providers to better understand their experiences and identify opportunities to work together to make improvements to the caregiver experience.

This is what we learned:

- * Family caregivers do not see themselves as caregivers. They are a son, daughter, spouse or

friend. They are doing what needs to be done. They are honoured to support their loved one, but they are overwhelmed. They find it very difficult to ask for help and they are having trouble coping.

- * The role of the family caregiver is 24 hours, seven days a week. Family caregivers spend a lot of time and experience a great deal of frustration navigating a complicated healthcare system. In addition to taking care of their loved one's personal needs, family caregivers describe their role as advocate and care navigator.

- * Both family caregivers and healthcare providers would like to improve

communication. Family caregivers don't always know who they should speak to. At the same time, healthcare providers often don't know who the family caregiver is. Both are looking for that point of contact.

- * Family caregivers would like to see more effective information sharing between healthcare providers and with family caregivers. At every stage, caregivers want to understand what is happening and what they should expect. They want tools to help them navigate the system. Healthcare providers recognize that they don't always have the information related to available supports and resources to share with the family caregiver.

* Family caregivers are overwhelmed with information and have a difficult time processing and understanding. Often times, they don't ask questions because they don't know what to ask, and they don't discuss their concerns about their role as the family caregiver because they don't want to create more stress for their loved one.

* Family caregivers want to be asked how they are doing, how they are coping and what they need.

* Healthcare providers believe they need more training on how to interact with family caregivers, how to present options and encourage them to accept help.

In addition to these themes, family caregivers shared feedback on some of the system issues that create unnecessary stress and anxiety. While some of these issues fall outside the scope of this project, The Change Foundation is committed to creating greater awareness of these issues at a provincial level.

These themes include:

- Challenges of navigating a complicated healthcare system
- Consistency, reliability, and training of personal support workers
- Respite and the need for greater flexibility, specifically in rural areas
- The need for affordable and reliable transportation, specifically in rural areas

Who we spoke to



121 family caregivers and **130 healthcare providers**, including **28 physicians**

60% answered never, rarely or sometimes when asked 'Do you feel there is good communication about your family member's/friend's care between doctors, nurses and other health care providers, and yourself?'

60.9% answered never, rarely or sometimes when asked 'Do you have the support you need to manage any anxieties, fears or worries you have?'

52.3% answered never, rarely or sometimes when asked 'Does your health care provider (doctor, nurse or other health care provider) ask you what you need to care for your family member/friend?'

"The caregiver often needs more support than patients There needs to be better communication amongst the entire circle of care and we need to speak their language" - Healthcare Provider

Improving the Caregiver Experience

As we move into *Phase 2 - Co-Designing Solutions with Family Caregivers and Healthcare Providers*, we will be focusing on three key areas of work:



Awareness and Recognition



Communication and Information



Education, Training and Supports

Healthcare providers and family caregivers will come together as equal partners to look at how to make improvements in each of these areas. As a first step, we will look at the theme of awareness and recognition. This will help to ensure healthcare providers better understand the challenges of being a caregiver and caregivers feel more comfortable in identifying themselves in the role.

This work will begin in the family health team setting as family physicians often have a natural relationship with both the patient and caregiver. With support from all partnering organizations, STAR Family Health Team will play a key role in helping to develop and pilot tools that can later be adopted by other health care organizations.



Sue's Story

As Sue reflects on her father's Alzheimer's diagnosis and the journey that followed, she recalls the toll it took on her whole family, but specifically on her mother, Barb, who was her dad's primary caregiver.

"Alzheimer's is a cruel disease. It was so hard to watch him deteriorate. Our health care team made the difference".

Tell me a bit about your dad, Gerry.

My father was a wonderful man, a kind and gentle giant. He had a successful career as a police officer and instructor at the Ontario Police College, and was a wonderful husband and father to my brother, sister and I. Five or six years before he was officially diagnosed with Alzheimer's, we began to notice things. He would forget his words. We would chalk it up to aging but we could see it was getting worse. He would hold an egg sandwich, and not remember what it was, or what to do with his breakfast.

What was the hardest part of your journey?

There were nights when my father would wander, hallucinate and become paranoid. He once woke up in the middle of the night and tried to get my mom out of the house because he believed people were coming to hurt them. It was a complete personality change. At that

time, my mother was scared and we needed to call 911 for help.

What got you through those difficult times?

A sense of humour helped. We had to appreciate the good times and inject humour through the bad. Our team of health care providers really made the difference. Everyone from the doctors, Alzheimer's Society, hospital staff, home and community care workers and those in the long-term care home that dad eventually moved to - everyone came together to care for our entire family.

My mom would get calls from her different case workers. They would check on her, give her tips and answer questions. They would also call me to ask how my mother was. I truly appreciated this because asking a caregiver how they're doing doesn't always give you a true picture of the situation. My mom would always answer 'fine', but she was 85 years old at that time, and it was getting more difficult to care for Dad.

In speaking to caregivers in our community, we heard how important it is to know what's happening and what to expect? How important was that for your family?

It's critical. We were so fortunate in many ways. We felt a part of our dad's care team and information flowed easily. It was scary to hear how dad's behavior might change but knowing in advance made it easier to cope. We knew



not to take dad's behaviour or words personally and knowing what could happen allowed us to create a plan so my mother knew exactly what to do if my dad's behavior escalated. My sister and I live an hour away from my mom, having a plan gave us peace of mind.

When you reflect on those who cared for your dad, what comes to mind?

Looking back, we didn't realize how difficult the journey would be. My dad's health care team made us feel like we were the team leaders and they were there to help us through. The emotional support we got was so appreciated. They would often ask how we were ALL doing.

We would have never been able to do it without their support.

Sue Rausa is a member of the Connecting the Dots Steering Committee. Sue hopes sharing her story will help to improve the caregiver experience.

Photo: Barb and Gerry in 2015 celebrating their 67th wedding anniversary. Gerry passed away a few short weeks later.

About Connecting the Dots for Caregivers

Connecting the Dots for Caregivers is a partnership between The Change Foundation and six health care organizations in Huron Perth. Together, with family caregivers, we are looking at ways to improve the caregiver experience by co-designing solutions, programs and resources that will ensure family caregivers feel valued, respected, engaged and supported in their important role.

The three-year initiative includes four phases:



Phase 1 - Planning and Engaging Family Caregivers - Fall 2016 to Summer 2017)



Phase 2 - Defining Areas of Focus and Co-Designing Solutions with Family Caregivers and Healthcare Providers - Fall 2017 to Spring 2018



Phase 3 - Pilot Services and/or Improvements with Partner Organizations - 2018



Phase 4 - Further rollout of services and improvements - 2018

PROJECT PARTNERS

Family Caregivers in Huron Perth
Huron Perth Healthcare Alliance
Alzheimer Society of Perth County
North Perth Family Health Team
One Care Home and Community Support Services
South West Local Health Integration Network
STAR Family Health Team

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FOR CAREGIVERS

Get Involved! We are looking for family caregivers to be part of future working groups. If you would like to be part of this exciting project, please contact Jennifer Hubbard at 519.527.1650 ext. 4219 or Jennifer.hubbard@hpha.ca



Follow the project on twitter @CC_Connecting